DOCUMENT RESUME

ED 425 574 EC 306 832

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TITLE	A Parent's Guide: Serving on Boards and Committees.
INSTITUTION	National Information Center for Children and Youth with Disabilities, Washington, DC.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	1998-10-00
NOTE	10p.
CONTRACT	H030A30003
AVAILABLE FROM	National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013-1492; Tel (voice/TTY): 800-695-0285 (Toll Free); Tel (voice/TTY): 202-884-8200; e-mail: nichcy@aed.org; Web site: http://www.nichcy.org
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Advisory Committees; *Advocacy; *Committees; *Disabilities; Elementary Secondary Education; *Governing Boards; Parent Empowerment; *Parent Participation; Preschool Education

ABSTRACT

This guide reviews common questions that parents of children with disabilities have about joining a board or committee, and discusses the unique strengths and skills that parents of children with disabilities bring to the group. The first part focuses on deciding to join a board or committee. Reasons to join are presented, including having a chance to help others; influencing the direction of activities, services, and policies; learning about programs that may benefit your child and other children; learning skills that will help in your present job or help to obtain a better one; and making a difference. The guide also discusses concerns about the time commitment, really making change happen, and how much responsibility will be given. Different types of committees and boards and their roles are described, including advisory groups to an agency or organization, boards with governing powers, standing committees, and ad hoc committees. Part 2 of the guide looks at some of the most common challenges after joining a committee or board, including getting others to volunteer, representing children with different kinds of disabilities, making your suggestions heard, and effective ways of keeping in touch with the people you represent. (CR)

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A Parent's Guide: Serving on Boards and Committees.

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EC 326832

NICHCY

EC306832

October 1998

A PARENT'S GUIDE

Serving on Boards and Committees

A publication of the National Information Center for Children and Youth with Disabilities

You started out stuffing envelopes at the kitchen table for your local disability group. Then you helped with the newsletter, and now you've been asked to serve on the board. Or maybe you advised your school district on how to make the playground accessible, and now they've asked you to serve on a special education task force or inclusion planning team. Whatever the group you've been asked to join, you may have a lot of questions, such as "Can I really do this? What's involved? Do I have the time?"

This *Parent's Guide* looks at some of the common questions parents have about joining a board or committee and discusses the unique strengths and skills you, as the parent of a child with disabilities, bring to the group. This guide is divided into two sections: deciding to join; and things to keep in mind after you join.

Part 1: Deciding to Join

To join or not to join...this is the big question most parents start off asking. It's nice to be invited, it's even nicer to have expertise to share, but...but... There are often many "buts" to be considered before you make your final decision.

So how do you go about deciding whether or not to join? Beyond finding out about the mission and activities of the board or committee (how to do this will be discussed later in this guide), undoubtedly there are personal aspects to consider before joining such as: "Do I have enough time?" and "How will this affect my family?"

It may help to know that lots of other parents have faced similar concerns about serving on a board or committee. Many parents find that the rewards of such service are well worth the time and effort. Here are some common questions parents have and the insights that other parents who have served in the past can offer.

Why should I serve?

Serving on an advisory group such as a board or committee can lead to real benefits for you, your child, and other children and youth with disabilities and their families. You have a lot to gain as well as to give. This includes:

☆ *Having a chance to help others.* Many parents who have served on a board or committee say that one of the biggest incentives for doing so is the opportunity to help others. They have "come up through the system" with their child, learned about their son or

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Mark's Experience

Mark is the parent of a nine-year-old daughter with developmental disabilities. He was asked to join the Ethics Committee of a large urban Children's Hospital.

He found that the committee was initially insensitive to the concerns of children with disabilities. At one meeting a nurse on the committee stated that she thought it was a shame that so many children with significant disabilities took up such a large percentage of beds in the Intensive Care Unit of the hospital. Mark was able to express the frustration that parents of children with disabilities feel when their children are not valued or seen as children who are loved, but who, instead, are just viewed in terms of their disability.

"I was also able to get the committee to appoint an adult with disabilities to the committee so they would have the voice of someone who was in the hospital a number of times as a child. It was a great feeling to see attitude changes in others because of my participation."

daughter's disability, received help from others more experienced in disability life than they were, and faced the challenges that come with having a child with a disability. Serving on the board of their local disability chapter gave them the chance to "give something back," share what they had learned, and help others learn. You may find this to be true for you. You've learned so much, and others can benefit from your experience and insights about raising a child with a disability.

☆ *Influencing the direction of activities, services, and policies.* Whatever type of group you serve on, you will have influence. Your opinion matters. On your local disability chapter's board, you will be deeply involved in planning and organizing the activities of the chapter. On an advisory committee, you can help shape how services or policies unfold. And on a governing board, you are part of the group that determines how an agency or organization conducts its business and serves its clients.

☆ *Learning about programs that may benefit your child and other children.* You may have already discovered that finding out what services are available for your child can be terribly time-consuming. As a board or committee member—particularly on groups advising or governing an agency—you are able to learn more about the programs and services that are available for children with disabilities. This puts you in an excellent position to help your family and other families find and use helpful services and programs.

☆ *Learning skills that will help you in your present job or help you get a better one.* You can add your board or committee experience to your resume—especially any special projects you work on. Serving with others may also provide contacts for future jobs. Even if *you* aren't job hunting, serving on the group may broaden your network and help your child when he or she begins to look for work.

☆ *Making a difference.* This is your opportunity to create positive change in the lives of individuals with disabilities and their families. On a local board, you can make decisions that affect others for the better. On an advisory committee, your concrete and practical knowledge about disabilities can help ensure that the decisions made by the larger organization are informed ones. And when you serve on a board where other members do not have much knowledge about disability issues, you can give an "insider's view" to people who otherwise might never know the needs of children with disabilities.

With all my responsibilities, how can I make time for this?

Yes, time is always a problem. You will need to go to meetings, and you may need to do reading and research between meetings. Find out how much of a time commitment is involved, and make sure you have—or can make—the time before you say yes. It may help to look at this time commitment as an investment: an investment in your family, in your community, and in yourself.

Can I really make change happen?

Usually, change happens when people become aware of what needs to happen, *how* it needs to happen, and care that it happens. If you're considering serving on your local disability chapter's board, then you (and the other members) care very much about children with disabilities and probably *know* what needs to happen to improve their lives. And rest assured, you can make change happen by getting involved, giving your time and energy to the board, and helping others to get involved.

Change comes more slowly when you're dealing with people who are not aware of the needs of children with disabilities and do not know what would be helpful. They simply may not have given it much

thought. You may be considering serving on a committee where you are the sole member with a disability perspective. Or, as a board member of your disability chapter, you may have many occasions where you must meet with members of the community, school system, or political system in order to persuade them about some issue. In this case, if you can teach people about the needs of children with disabilities and direct them to the appropriate resources, then you can make a difference.

"Making a difference" may mean persevering through a gradual process of change. Creating change in a system or community usually involves several steps:

1. Tell people about children with disabilities and their problems and concerns.

2. Help them understand what the problem is and why it is important.

3. Explain the possible solutions to this problem. Be willing to brainstorm for other potential solutions.

4. Personalize the situations, so they are real. Often this means telling true stories about how problems have been effectively resolved.

5. Identify resources available to help solve the problem(s). Tell people several places they can contact for assistance, hand out written materials, give out names of specialists in your area, and provide the names, addresses, and phone numbers of people (legislators, local officials, etc.) to contact in order to bring about the desired result.

6. Offer to help.

Once people are aware of the needs, understand the problem, believe there is a solution, see themselves as part of that solution, and know who to call, most problems can be addressed. It may take time, but someone (often that "someone" will be you) needs to be persistent. If you can do this, then you can bring about changes that will improve the lives of the children and families you represent.

How much responsibility will I have?

The amount and type of responsibility you will have will depend in large part upon what kind of group you have joined. Parents have many opportunities to serve on an advisory group. Here is a brief overview of some types of groups on which you might serve and what each type may mean in terms of time and duties.

The board of your local disability group. Perhaps the most common opportunity for service is on the board of a local disability group. For example, you may be a member of your local learning disabilities or epilepsy chapter and one day be nominated or invited to serve on its board. As a board member, you would probably be expected to attend a monthly meeting where you and other board members would plan activities for the chapter and discuss issues related to chapter members and your community. Activities of such boards can include:

- ☆ writing a newsletter to communicate with members of the chapter;
- ☆ organizing fundraisers such as a yard sale, dinner, or art show;
- ☆ organizing speakers for the monthly meeting;
- ☆ handling membership dues and other group finances; and
- ☆ representing the chapter's disability-related interests locally or within the state.

While you may imagine that serving on such a board would be intimidating and formal, you will probably find that the opposite is true. Most boards of local disability groups don't have much money or a lot of staff or volunteers to supervise. You and the other board members may do a lot of the work yourselves, including making phone calls to round up people for activities, contributing information to the newsletter, putting newsletters into envelopes and addressing them to members, and so on. Yet these activities are the nuts, bolts, and gears that run the organization and provide the community with information about the disability and the services available to assist people with that disability and their families.

You've learned so much, and others can benefit from your experiences and insights about raising a child with a disability.

Advisory groups to an agency or organization. Within your community or state, there may be many opportunities to serve as part of an advisory group to an agency or organization (e.g., a hospital, a park or recreation department, or a local preschool). For example, your school district

Judy's Discovery

When Judy's daughter was six years old, Judy began serving on the board of her local spina bifida chapter, which had helped her when her daughter was much younger.

"One of the things I learned," says Judy, "is that you don't have to be brave or a genius to get things done. You just have to stick with it."

may establish a special group to give advice on special education policies, school reform, inclusion, or another issue where input from certain groups or the community at large is critical. Your park and recreation department may set up an advisory group to learn more about how it can address the special needs of people with disabilities.

Generally speaking, advisory groups do not have responsibility for planning activities, fund-raising, or decision making for the organization. Their role is *to advise*—they study the issue at hand, collect input from members of the advisory group and perhaps externally from the community, and report back to the larger agency. Your duties on such an advisory group would probably include attending meetings, gathering information from your community, and certainly contributing your own perspective and expertise. The group may also have to prepare recommendations for the agency. Some advisory groups are permanent, and others will be disbanded after they have served their purpose of providing guidance and insight.

Advisory groups typically bring together individuals with differing skills and perspectives. Sometimes the central issue is disability-related, and all members have expertise in some aspect of disabilities. For example, you may represent the "voice" of individuals with visual impairments. Another member may bring knowledge of deaf issues to the table, while still another may speak to the needs of children with mental retardation. But just as often the advisory group is not focused exclusively on a disability-related topic. You may be the only "voice" for disabilities on the committee. Other group members may represent other perspectives entirely. In this way, the advisory group pulls together the wisdom and insight of various segments of the community.

Boards with governing powers. This type of board has a great deal of formal responsibility and authority for a specific organization—for example, a company, an independent living center, a service provider. The board usually establishes the organization's policies and rules, and governs or supervises specific programs or services offered through the organization. Board members typically have fiscal responsibility, meaning that they authorize the spending of monies and can be held responsible (liable) for mismanagement of funds or other resources. Fundraising may be part of the board's duties. The board may hire the Director or President of the organization and ultimately be responsible for ensuring that he or she implements programs and services as expected. The board also has responsibility for enhancing the public image of the organization; organizing short- and long-term planning; and hearing input, both positive and negative, from the customers of the agency.

These more formal boards typically require members to meet regularly, be well informed about the organization the board oversees, make fiscal and policy decisions about the organization's activities, and so on. There may be an Executive Committee within the board—the President or Chair of the board, a vice-president or vice-chair, a treasurer, and a secretary. You may hear terms such as standing committee and ad hoc committee (defined in the box below). These are smaller groups that have special, separate tasks within the board.

Many parents find themselves serving on a governing board after they have had some experience serving on other advisory groups or the boards of local disability groups. While each board member clearly has a high level of responsibility on a board with governing powers, the opportunity to make significant changes and to ensure quality services or products can be very satisfying.

Two Types of Board Committees

Standing committee—a permanent committee that studies an issue or problem in depth. After investigating the issue, the committee makes a report to the Board as a whole. The Board then uses this information as a basis for making decisions. Some typical standing committees are: Program, Finance, Recruitment and Nominating, Development, and Public Relations and/or Legislative.

Ad hoc committee—a temporary group organized for a special purpose. For example, an ad hoc committee could be organized to track the reauthorization of a particular law, or it could be formed to coordinate a community fair.

How do I find out more about the board or committee?

Before you join, it's a very good idea to acquaint yourself with various aspects of the group. Knowing more will help you decide if, indeed, you want to serve. If you do join, knowing more about the group will also help you assume your responsibilities more quickly. Here are some issues to consider before you join and some ways in which you can gather the information you need about the group.

What is the purpose or mission of this group? If you've been nominated or invited to serve on your local disability chapter's board, you probably already know what its purpose or mission is. But you may be thinking of joining an unfamiliar group, such as a countywide advisory panel on special education, the independent living center's board, or a state-level committee. In these cases, knowing the purpose of the agency organizing the advisory group may help you decide if this is a group you want to be involved with. Ask the leader of the group (this person may be called the Board Chairperson, Executive Director, or some other title) for written material about the organization and about the advisory group. Don't hesitate to ask questions if you find anything confusing about the organization or its official materials.

Also ask any practical questions you have about serving on the group. Some typical questions you may want to ask are listed in the box on the right. It's vital to know specifically what you will be asked to do and what is expected of you.

Part 2: After You Join

So, after weighing your options and finding out more about the group, you've decided to join. Great! Now what?

While this new experience will likely prove exciting and interesting, there are several challenges you may encounter when working on the board or committee. These may vary, depending upon the type of group you've joined. Let's look at some of the most common challenges you may have.

I'm on the board of my local learning disabilities chapter. How do I get people to help out?

Sometimes it may seem as if no one but you and your fellow board members are concerned about the chapter's welfare. Where are the members at meeting time? Where are they when there is work to be done? Is all this work really worth it?

Yes! Everyone is busy, and having a child with a disability can make you even busier than most. It's hard to find people to help out with planning activities and seeing them through. That's why the board members of local groups often end up doing so much of the work. But consider this story of success: When Marta joined the board of her local LD chapter, the group was about to disband for what appeared to be lack of member interest. However, when faced with the likelihood of losing the chapter, members protested. They didn't really have time to come to a lot of meetings, but they were definitely interested in learning disabilities. The majority of the members had a child or other family member with LD. So the board began a newsletter to communicate regularly with members. This allowed everyone to get information without going to a lot of meetings. They held small fundraisers—a yard sale was the most successful—and hired a part-time person (actually, one of the parents) to answer questions about LD and direct people to local, state, and national resources. Their membership grew steadily. They purposefully planned activi-

Some Questions You May Wish to Ask

Exactly what will my responsibilities be?

How long will I be expected to serve? (Most boards and advisory committees require you to commit to serving for a specific amount of time, usually 1-2 years.)

How often do you meet? At what time? Where?

Are there any travel requirements?

Do you provide orientation or ongoing training for new members?

Do you provide liability coverage? (Liability insurance protects you if a civil suit is lodged against the agency on whose board you serve. Make sure the group has this protection for members.)

What authority does the advisory group have for aspects such as: the budget, services/programs/policies, personnel, public awareness, legislative or advocacy activities, and review of performance?

Who are some of the other members, and what groups or concerns do they represent?

ties where volunteers worked short amounts of time, maybe making a half dozen phone calls or stuffing envelopes with the newsletter. Do board members still end up doing most of the work? Yes. Is it worth it? They think so, because they are making a difference and helping families find the support they need.

I'm the only member whose child has a disability. What do I contribute?

As a parent of a child with a disability, you have much information to share. You can explain the needs, concerns, and joys of living with a child who has a disability. You know the day-to-day effort and emotional side of raising a child with a disability and the needs of families like yours. Many people who do not have your experiences cannot even imagine this way of life. You can help other members by talking about your life and the experiences of your children. When you do this, you help the members better understand the issues that are important to you, your family, and other families. Your experiences remind other members that children with disabilities need to be considered in the agency's decisions. You can do all this just by being present at meetings and sharing what you know.

I know my child, but how can I represent children with different kinds of disabilities?

On certain kinds of advisory groups, you may be the member who represents the "disability" voice. This may make you uncomfortable—you know your child but you'd never describe yourself as a disability expert. However, advocating for one child is not very different from advocating for many. Figuring out a child's needs, talking about those needs clearly and positively, working for concrete results, and increasing others' awareness of disability issues are major concerns for all parents of children with disabilities. They are also critical skills. Your experience provides an excellent background for representing families of children with disabilities. As a parent of a child with a disability, you also understand the emotional side of advocating for your child, and this is a very similar experience for all families.

If you are serving on a group where you represent others within the disability community, you may find that the key to doing your job well is keeping in touch with other families. Disability-specific parent groups are a great way to establish contact with other parents and learn more about their particular needs and those of their children. You can identify the parent groups in your community by talking to teachers and other parents, looking on the bulletin board in your local library or asking the librarian, or calling the parent training and information (PTI) center for your state. (NICHCY can put you in touch with your PTI and with state groups, who may be able to refer you to local chapters.) Once you've identified the groups in your area, ask to get their newsletters. If you have time, go to their meetings, let them know your role on the advisory group, and ask for their suggestions and input. (How to do this will be discussed more on the nextpage.) These same people will be the ones you then can contact with any information your board, committee, or task force wants to get out into the local communities.

Sarah and the PTA

Sarah, the mother of a daughter with a disability, was asked to join the PTA Board of a school that had recently started including children with disabilities in the general education classroom. Serving on the PTA's board gave her the opportunity to answer questions, calm fears, reassure others, and educate the PTA about the many abilities of the students receiving special education.

"I helped them see that those students were more like their typical peers than they were different, and that we all have abilities and disabilities." Sarah was also able to tell the PTA about many resources on successful inclusion practices. "Soon you didn't hear the words 'special education' students very much—they were all just students."

Sometimes I feel like the "token" parent of a child with a disability. How can I make sure my suggestions are heard?

Some boards and committees need to include a parent such as yourself, and the group has no real idea of the value of this position. You need to let members of the group know that you have valuable ideas and knowledge, but how? This may involve several steps.

☆ *Find out as much as you can about the group you have joined.* This guide has talked about ways to do this. Find out about the other individuals in the group, their backgrounds and interests, their knowledge and experience about disability issues, and their perspective on education or related issues such as dropout prevention or school sports. When you get to know people, you will find that you can plan what you want to say and anticipate many of their questions. As you gain more experience, you will begin to understand where you fit in and how you can contribute

effectively. You will also find that you will feel more comfortable, and so will they.

☆ *Find out what the primary issues are for the members of this group.* Find out what other members feel is important, and volunteer to do something that will add to that effort. Try to find a job that is highly visible—for example, working on the newsletter—and will put you in contact with influential members of the board. This is a good way to have your skills recognized.

☆ *Get to know the other members.* Start conversations with people before and after meetings. You will know a little about people from what they say in the meeting; after the meeting, ask questions that encourage them to talk further. People like to talk about what they know. You can let them know about you, too.

☆ *Stay out of any areas of disagreement or conflict among group members.* Sometimes there may be tension, conflict, or "past history" between certain members. Try to stay out of these conflicts, if possible. You don't want to start by being seen as on one side or another.

☆ *Represent disability issues thoughtfully.* Be sure to present yourself as caring for all families and people with disabilities, rather than just your child with a disability and your personal situation. Try to appreciate the views of those who are not parents of children with disabilities. Chances are that they have children, too, and while they don't have to deal with all of the same parental issues that you do, they do understand family issues. You probably have more in common than you think. Remember this as you discuss issues with other members, especially when you disagree.

Often it is necessary to compromise in order for the group to reach a decision. Compromise is different from "selling out." Compromise means that each person gives and takes to bridge the differences that are stopping progress. Be willing to listen and weigh others' opinions. Don't insist that your opinion is the only correct one. It is important to be seen as a person who can negotiate and compromise when necessary. In the end, your opinion will be heard more often if you are seen as a reasonable, thoughtful individual who knows how to listen as well as speak up.

Your experience provides an excellent background for representing other families of children with disabilities.

What are effective ways to keep in touch with the people I represent?

Keeping in touch with the families and children with disabilities you represent is a critical part of serving on an advisory group. The best way to know what other families need is to talk to them regularly.

As mentioned earlier, you might want to visit individual group meetings and talk with people in person. When you meet with people, either one-on-one or in a group, listen carefully to make sure that you understand their service needs and ideas. Repeat back what you think they're saying, so you're sure you understand. You need to know or find out how existing services fit into these needs and where the gaps are, so you can take their comments and concerns back to the advisory group. Make sure that your name, phone number, email, and address are given out so that people can contact you with their concerns and ideas.

Communication is a two-way street, of course. You'll need to report back to these groups to let them know what the board or committee is doing about their concerns. If you have the time, it's good to "report" on committee activities in person, but you can also mail your "report" to someone in the group who can read it at the meeting. You can write short announcements or stories for their newsletters. (One story can be sent to several newsletters.) This back-and-forth communication is the key to keeping in touch with the people you are representing.

☆ ☆ ☆ ☆ ☆

Serving on a board or advisory committee has many rewards and benefits. You will have the opportunity to develop skills such as listening, negotiation, public speaking, and leadership. In addition, you will gain knowledge that may help you and others gain access to needed services. You can also share the knowledge you have gained raising your child and can help others in the same situation. It is also important that parents such as you serve on advisory groups that guide organizations whose main purpose is not disability-related. As a parent of a child with disabilities, you can give people with disabilities a voice in new and different arenas. You bring a unique perspective to the table, one that only a parent of a child with disabilities can bring, and that perspective needs to be heard.

Congratulations on your appointment and good luck!

NICHCY Parent's Guide is published in response to questions from individuals and organizations that contact the Clearinghouse. In addition, NICHCY disseminates other materials and can respond to individual requests for information.

NICHCY would like to express its gratitude to our Project Officer, Dr. Peggy Cvach, at the Office of Special Education Programs, U.S. Department of Education. We would also like to thank Sherri Coles, the author, for her generosity and patience.

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